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van Betuw *Orphanet Journal of Rare Diseases* 2010, **5**(Suppl 1):O8
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ORPHANET JOURNAL OF RARE DISEASES

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The impact of a small parental network: how 11q improved research, knowledge, contacts and support

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From 5th European Conference on Rare Diseases (ECRD 2010)
Krakow, Poland. 13-15 May 2010

After the birth of our daughter, Geertje Jongman, and being told about her very rare chromosomal disorder, my husband and I experienced what so many parents did: not knowing anything, feeling alone, with our world turned upside down. Many years later we decided to start a European network and thanks to immediate support of other parents, some researchers/scientists and the internet; we managed to build it up. I resigned some years ago, but it is still alive and kicking!

The European Chromosome 11q Network was formally founded in 1997. Looking back and comparing it to other small networks, I see that the way we did it, was good:

- Set a goal
- Find co-workers
- Make a plan and put it in a time frame
- Use modern ways of communication
- Get money
- Consider the implications on your personal life and then decide if you still want to do it.

From the start parents decided that they should set goals and stay in control. A strong and positive network is able to find people who know about organisation, finance, modern ways of communication and most important: they try to understand each other and accept differences in culture and habits. Outcomes from our network: 6 conferences, several research projects and results and support for 'new' families. Most important: never being alone anymore.

Moreover 11q or as it is known now, the 'European Chromosome 11 network', is sometimes mentioned as an example how things can be done successfully at the European level. However, the network now stands for a new issue: is it necessary to set new goals, especially for the ultra rare chromosomal disorders? How to deal with new ways of communication like social media, e-health and online consulting? Is it possible to stay alive as a small network? It is interesting, and a challenge once again.

Published: 19 October 2010

doi:10.1186/1750-1172-5-S1-O8
Cite this article as: van Betuw: The impact of a small parental network: how 11q improved research, knowledge, contacts and support. *Orphanet Journal of Rare Diseases* 2010 **5**(Suppl 1):O8.

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